DRVD
CONFIDENTIAL REPORT

INVESTIGATION INTO THE DEATH OF S.N.

26-YEAR-OLD MALE RESIDENT OF THE NORTHERN VIRGINIA MENTAL HEALTH INSTITUTE WHO DIED AS A RESULT OF ACUTE HEMORRHAGIC PANCREATITIS

DRVD Case No. 98-0163
Department for Rights of Virginians with Disabilities
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I. INTRODUCTION

This report is a summary of the findings of the investigation by the Department for Rights of Virginians with Disabilities (DRVD) into the death of SN, a 26-year-old male resident of the Northern Virginia Mental Health Institute (NVMHI) who died as a result of acute hemorrhagic pancreatitis. On June 7, 1998, SN was transported from the NVMHI to the Fairfax Hospital where he was admitted to the emergency room. SN died in Fairfax Hospital at approximately 11 PM on June 8, 1998.

In January of 1987, at age 14, SN was admitted to the Dejarnette Center, a facility for adolescents run by the Virginia Department of Mental Health, Mental Retardation and Substance Abuse Services (DMHMRSAS). He remained in the care of DMHMRSAS for the remainder of his life. In March of 1998, at age 25, SN was transferred to NVMHI.

DRVD directed this investigation of abuse and/or neglect of an individual with mental illness pursuant to the Protection and Advocacy for Individuals with Mental Illness of 1986 (PAIMI).

This investigation included the following:

A. Review of SN's records accumulated by the DMHMRSAS during the period that SN remained in its care.

B. Review of the records of Fairfax Hospital made on June 7 and 8, 1998.

C. Review of the report of Dr. Catherine Leslie prepared at the request of the

Office of the Attorney General for Virginia. (See Attachment.)

D. Review of the Root Cause Analysis prepared by the DMHMRSAS including written and verbal interviews with NVMHI staff.

E. Interviews with SN's mother and her representative Dr. Sal Fiscina; Charles Johnson, Senior investigator, Virginia Department of Health Professions; and Dr. William Wittlin, Psychiatrist and Associate Professor, Cornell Medical School.

F. Review of the autopsy prepared by Fairfax Hospital.

G. Review of "NVMHI Amendment to Plan for Continuous Improvement" prepared as part of settlement agreement entered into between DMHMRSAS and the United States Department of Justice (DOJ).

II. BACKGROUND

A. The Facility

NVMHI is a short-term mental health treatment facility located in Fairfax County, Virginia that serves the Northern Virginia community where SN resided prior to his hospitalization in 1987. As a result of previous treatment deficiencies, NVMHI was subject to suit brought by the U.S. Department of Justice. Prior to the death of SN, the DOJ and DMHMRSAS entered into a Consent Decree which set out specific requirements governing the provision of non-psychiatric medical care. Subsequent to the death of SN, representatives of the DOJ toured the facility, and interviewed NVMHI staff as well as the mother of SN and her representative. As a result of this investigation, the terms of the consent decree were revised.

As a result of the death of SN and another patient at the NVMHI and the subsequent investigations of these deaths, seven members of the clinical staff resigned in lieu of termination. This included SN's psychiatrist, Dr. John Rogers, and the Medical Director. On June 12, 1999, the Medical Director's successor, Dr. John Follansbee, also resigned.

B. The Patient

Mental Health Treatment: SN was a twenty-six year old male with a diagnosis of Obsessive Compulsive Disorder and Bipolar Disorder. He resided at the NVMHI from March 17, 1998 until his death on June 8, 1998. SN was first hospitalized in a private facility at age 14 due to agitation, defiance and violent behavior. Shortly thereafter (January 29, 1987), he was admitted to the

Dejarnette Center, a facility run by DMHMRSAS serving adolescents suffering from mental illness. He remained at Dejarnette until January 11, 1988 at which time he was transferred to Western State Hospital (WSH). SN remained a resident of WSH until his transfer to NVMHI. His transfer to NVMHI was undertaken in order to facilitate his eventual reintegration into the community.

SN's primary diagnosis upon his admission to Dejarnette was Schizoaffective Disorder. His diagnosis was subsequently changed to Obsessive Compulsive Disorder and Bipolar Disorder for which he was prescribed Lithium, Benedryl and Mellaril. Prior to his transfer to WSH, it was noted that "a trial of haloperidol resulted in extreme rigidity" and other symptoms suggesting the onset of neuroleptic malignant syndrome (NMS). At WSH, SN continued to demonstrate immature, oppositional, provocative, bizarre, and ritualistic behaviors. Psychological testing also indicated significant learning disabilities which impaired his ability to learn. Upon his transfer from WSH to NVMHI, his diagnosis was Axis I: Obsessive Compulsive Disorder, Oppositional Defiant Disorder, Mood Disorder due to antidepressant use with manic features in remission; Axis II: Borderline Intellectual Functioning; Axis III: H/O tuberculosis, Hypercholesterolemia, Iatrogenic Hypothyroidism; Axis IV: Severity of Psychosocial Stressors (continuous hospitalization; lack of education and work skills; lack of social skills) and Axis V: GAF present: 30. The discharge summary recommended that SN be placed in a well-structured setting where contingent consequences could be imposed depending upon his behavior.

Upon SN's transfer to NVMHI it was stated in his treatment plan that a gradual transition to a community residence program could begin once he had demonstrated a period of stability. Dr. Leslie states in her September 8, 1998 report that NVMHI primarily focused on controlling SN's obsessive compulsive behaviors rather than his inappropriate social behaviors and limited living skills. SN's psychiatric diagnosis remained unchanged during his stay at NVMHI. With respect to SN's stay at NVMHI, the final discharge summary authored by SN's primary psychiatrist, Dr. John R. Rogers, states:

> [SN] adjusted well to the unit, was provided blue band level of privileges and had daily passes to participate in community reintegration programs with the staff. He attended his groups and activities, including group therapy, recreational, and occupational therapy. His mood remained stable, without overt signs of mania, and he did not voice any psychotic symptoms. He continued to manifest thinking and behavior consistent with his Obsessive Compulsive Disorder with repetitive hand washing and perseveration, asking repetitive

questions, and obsessing about numbers divisible by 2.

Physical Health Treatment: During his 11.5 years as an inpatient, SN was diagnosed with a variety of physical problems. While at Dejarnette, SN was found to have been exposed to tuberculosis. In addition, he was diagnosed with cholesterolemia and hyperlipidemia with cholesterol of 309 and triglycerides of 447. While at WSH his cholesterol and triglyceride levels were monitored. In 1994, with his cholesterol at 257 and triglyceride level at 707, an internal medicine consultation was conducted. It was recommended that SN be placed on a vigorous exercise regime and a low calorie/diabetic diet. In 1997, a treatment goal was written to teach SN about his need to comply with his prescribed diet. Notes in the record state that SN had great difficulty limiting his food intake and that he was unable to follow his diet. A medical consultation suggested the use of medication to control SN's cholesterolemia. No medications were subsequently prescribed. However, both his cholesterol and triglyceride levels had decreased by 1/13/98. SN's propensity to sneak food not on his diet continued to be a problem. Two other potential and related health problems were identified. SN continued to show an elevated thirst and constant need to drink water. In addition it was noted that there existed a family history of Diabetes Mellitus.

At NVMHI, the previously diagnosed health problems were monitored. Elevated glucose levels were noted and the possibility that SN suffered from Diabetes was also noted by Dr. Rogers. A significantly elevated glucose level of 170 was reported on 5/18/98. Dr. Rogers responded by ordering a follow up test to be drawn on June 15, 1998 at the regularly scheduled blood work-up.

III. EVENTS LEADING UP TO THE DEATH OF SN

On the morning of June 6, 1998, SN was noted to be increasingly lethargic with some unusual disorientation, stumbling gait, increased thirst and reports of vomiting during the previous day. The Nursing Supervisor was notified of SN's condition. He then notified the on-call physician. The on-call physician was scheduled to see SN the following morning.

On the morning of June 7th, a pass to leave the hospital with his mother was postponed in order to allow the doctor to see SN and permit the NVMHI staff to monitor his physical condition. Dr. Rokoski, who was on-call, along with the nursing supervisor visited with SN at 11:25 a.m. that morning. Dr. Rokoski ordered lab tests for the following morning and noted, among other things, that he felt SN's "dullness" was likely secondary to his hyperthyroid condition for which his prescription for Synthroid had just been increased. His blood pressure was elevated but nursing notes suggest that it appeared to be doing better. By the afternoon, SN was reported to be "groggy and sluggish," he was observed to be

dressed inappropriately (pants on backwards and shirt on inside out). His thirst was increased and he was repeatedly requesting liquids.

SN's symptoms continued to be monitored by the nursing staff. At 6:15 p.m., an entry in the nurse's log indicates that SN was found on the floor after falling and that he was complaining of not being able to see well and of dizziness. Jerky hand movements and sluggishness were also noted. The nurse's impression was that SN was not his "usual self." It was also noted that SN complained of choking and required assistance eating dinner that evening. SN's symptoms continued throughout the evening. Again the Nursing Supervisor was notified who in turn notified the on-call doctor. The doctor ordered that SN's medications be withheld and the doctor was scheduled to see SN on the morning of the 8th. At 9 p.m., the nursing staff assisted SN in calling his mother in order to convey to her the seriousness of his condition. The nursing staff encouraged SN's mother to contact the Nursing Supervisor to expedite appropriate treatment. This strategy proved successful and, after SN's mother called the Nursing Supervisor, SN was transported to the Fairfax Hospital ER on the orders of the on-call physician, Dr. Rokoski. (Fairfax Hospital is located adjacent to NVMHI.)

Once SN was admitted to Fairfax Hospital, intervenous fluids and insulin were begun. SN was diagnosed with problems associated with DKA (diabetic ketoacidosis). Due to his severe agitation, SN was then administered 2 mg IV haloperidol at 3:00 a.m. on the 8th of June. SN's temperature rose to 108 degrees during his course of treatment in the ER. Although extreme measures were instituted to combat SN's failing condition, SN died at 11 p.m. on the 8th of June. An autopsy was performed and the cause of death was determined to be acute hemorrhagic pancreatitis.

IV. FINDINGS AND CONCLUSIONS

As with many complicated deaths, the responsibility for SN's death may not be affixed with absolute certainty. For the purposes of this investigation, it is my conclusion that DMHMRSAS, NVMHI, Dr. Rogers and Dr. Rokoski are liable for SN's death. The liability of each will be delineated below. It must be noted that these conclusions are in great part made in reliance on the report of Dr. Catherine Leslie. The complex medical history and medical mistreatment of the deceased could only be analyzed by a physician with expertise in the mental health system.

Cause of Death: It was the conclusion of Dr. Catherine Leslie that SN "died from DKA and acute, severe hemorrhagic pancreatitis." The underlying cause of death was twofold: (1) the development of diabetes mellitus which went untreated and then developed into diabetic ketoacidosis (DKA); and (2) a continued elevation of SN's triglycerides which was the most likely cause for SN's pancreatitis. Her conclusions are founded on the lab work performed at NVMHI (showing among

other things elevated glucose levels) as well as symptoms such as a groin fungal infection and the multiple notations of SN's high degree of thirst and increased water intake. Blurred vision (reported by SN the day before his death) is also listed as a symptom of uncontrolled diabetes. SN's fluid intake was treated over a long period of time as part of his obsessive-compulsive disorder. This may have lead the medical staff to overlook its significance as a symptom of diabetes. There was also a family history of diabetes that was known and recorded in SN's medical history. Dr. Leslie states "As increased thirst is a cardinal symptom of diabetes, it is unfortunate that the elevated glucose and this symptom were not linked." She also states "If even the provisional concern for possible diabetes mellitus had been placed prominently in the chart, the patient's course at the beginning of his acute illness may have been different."

The Liability of WSH: For the 11.5 years prior to SN's death, he was in the care of DMHMRSAS. Given his mental condition, it is beyond question that the Department assumed both the responsibility for monitoring his mental health as well as the responsibility to provide appropriate medical treatment. While the immediate failures leading up to SN's death lay within the control of NVMHI, the development of diabetes may well have been diagnosed earlier while SN was a patient at WSH. While at WSH, lab tests revealed elevated glucose levels and increased thirst was observed. These findings were viewed in the context of SN's compulsive disorder rather than as symptoms of a physical problem. The family history of diabetes was also noted. It is likely that SN's diabetes was inadvertently controlled at WSH due to the dietary limitations placed on SN's food intake. SN was, in fact, placed on a "low calorie/diabetic diet" to control his hyper-cholesterolemia. As a result of this diet, it appears that along with reduced cholesterol and triglycerides, SN's glucose level was being controlled. (Lab reports on 1/13/98 report a glucose level of 97.) While no diagnosis of diabetes was made at WSH, they closely monitored his glucose levels. Medical literature suggests the following:

> The diagnosis of diabetes can be established or excluded with certainty. Even when diabetes has a gradual onset or its symptoms are subtle, it can be positively diagnosed by establishing blood glucose criteria. Although few patients need it, the 75-g oral glucose tolerance test is the definitive way to establish the diagnosis or rule it out. Screening for diabetes ... is indicated ... in persons at high risk.

Persons with strong family histories or suggestive symptoms are considered at high risk. Certainly, SN with his family history, uncontrolled thirst and an ongoing history of polydipsia and polyuria fell within the high-risk category. There is no record that any definitive test for diabetes was conducted while SN was a patient at WSH. Dr. Leslie's admonition that "[I]f even the provisional concern for possible diabetes mellitus had been placed prominently in the chart,

the patient's course at the beginning of his acute illness may have been different[.]" applies equally to WSH.

An additional concern is raised by the decision to transfer SN to NVMHI. The rationale for SN's transfer to NVMHI was to facilitate his reintegration into the community. Dr. Leslie opines that WSH and NVMHI differ significantly in their approach to patient management. WSH, a long-term facility, employs a more paternalistic approach to its patients. This is exemplified by the control it can assert over the dietary habits of the residents. At WSH patients are served individualized meals in their rooms. In comparison, NVMHI allows the patients to eat in a cafeteria where they have greater choice in selecting the food they eat. Additionally, the lack of control over SN's diet would be exacerbated at NVMHI when SN participated in such re-community-integration activities such as trips to Wal-Mart, 7-Eleven, Food Lion and McDonald's. In the discharge notes from WSH, it is noted that SN had received "much patient teaching related to his diet and need for exercise." It was recommended that SN be placed in a "well-structured environment, such as a ward where his behaviors can be contingently consequenced." It had been noted by WSH staff that SN "has great difficulty with limiting himself with food/drink and will overeat and make himself sick if not monitored closely" and SN "lacks good judgement when making edible purchases." In the 10/24/97 Treatment Planning Conference, Dr. Wampler notes that the "Low calorie diabetic diet is not sufficient to keep his cholesterolemia within range" and that SN was non-compliant with his diet. On 2/6/98, Clinical Progress Notes states SN's "cholesterolemia is not being controlled through his diet as [SN] is non-compliant. [SN] will 'sneak' food not on his diet as often as available. The team discussed discontinuing the plan because of his non-compliance, but it is the only approach feasible."

Dr. Leslie opines "Demonstrating eating behaviors which were dangerous was considered a sign of active illness with inability to care for himself." Given SN's total lack of progress in this regard while at WSH, it was foreseeable that upon his transfer to NVMHI, the facility would have even greater difficulty controlling his eating habits. SN's ongoing inability to comply with his diet coupled with a diagnosis of diabetes should have precluded his transfer to NVMHI.

The Liability of NVMHI: While WSH may be faulted for failing to diagnose SN's diabetes, ultimately SN's decline and ultimate death was due to the failure of NVMHI to medically assess his physical condition despite a well documented history of eating disorders. Dr. Leslie opines that SN's "eating behaviors over the next few months [after his transfer to NVMHI] can best be described as a kid in a candy store." SN's behavior appears to be directly related to the lack of control asserted by the institution coupled with the vastly increased ability of SN to obtain food whether from the cafeteria or the various community outings. The failure to control SN's food intake led to both the elevated levels of cholesterol,

triglycerides and glucose. This resulted in the DKA and acute pancreatitis which caused SN's death.

While SN's eating behavior resulted in part from the NVMHI milieu, it may have been significantly curtailed had the staff been aware of dangers presented by SN's diabetes. This failure lies at the feet of the NVMHI medical staff. Upon his transfer to NVMHI, SN presented with Hypercholesterolemia and a clearly established inability to manage his own eating habits. While the record establishes that SN's cholesterol levels were quite high and that the situation was to be closely monitored, there appears to be no doctor's order that SN be restricted to a low cholesterol diet. Although SN claimed to be complying with his diet, the staff's observations of his eating habits clearly reflect that he was non-compliant. Unfortunately, Dr. Rogers did not consider this a significant problem and SN was issued a green band giving SN greater autonomy. With this freedom, SN was able to more easily acquire inappropriate types and amounts of food. On 5/26/98, the record states "SN does not always accept his decreased cholesterol diet, he is observed eating large amounts of food, does not adhere to his diet - will eat what's given to him however eats as he chooses between meals. [Patient] Education continues concerning his low cholesterol diet." Dr. Leslie notes that "At WSH the patients [sic] lack of behavioral control with his diet (not his verbal expression of understanding) would have precluded - and did for years - an increase in his level." Dr. Leslie opines "Basically, I think his rising cholesterol and triglycerides (and development of diabetes mellitus) were indicative of [SN] being allowed to eat himself to death."

It also appears that Dr. Rogers and the internal medicine physician failed to appropriately respond to elevated blood levels which were reported on 5/18/98. SN's blood levels indicated a rise in SN's glucose from 103 on 3/18/98 to 144 on 4/17/98 to 170 on 5/18/98. The accepted indicator of diabetes at that time was a level above 140. According to Dr. Leslie, the appropriate medical response to these findings would be to repeat the tests within a couple of days and not order them to be drawn one month later as Dr. Rogers had ordered. Again it should be underscored that these blood levels should have been analyzed in the light of SN's polydipsia and family history.

In addition to NVMHI's failure to properly diagnose SN's diabetes and control his dangerous eating habits, NVMHI medical staff also appears to have mismanaged the acute illness he presented which began on June 5, 1998. Dr. Leslie opines that "it is highly inappropriate to hear about a patient who is lethargic and disoriented with stumbling gait and not personally see the patient or order transfer to someone who can evaluate the patient immediately, i.e. an ER. These symptoms of a change in mental/neurological status are indicative of an emergency." Dr. Leslie also found that the on-call physician's evaluation of SN in the morning of June 7, 1998 to be "very inadequate given the symptoms." She suggests that the on-call

physician should have ordered a repeat of the lab work immediately and not for the next morning as was done. Later on the 7th, SN was found on the floor after falling. He complained of blurred vision and dizziness. Jerky hand movements were noted as was general sluggishness. These symptoms required that SN be personally evaluated by the physician immediately.

There also appears to have been a systemic problem in the ability of the nursing staff to access medical assistance for SN. From the written statements of the nurses involved as well as statements made by a nurse to SN's mother, it appears that the nurses felt precluded from directly pursuing the medical care they perceived that SN needed. Other than to advise the supervising nurse, who was not on the unit, of SN's condition the nursing staff believed they had no other permissible options. It was reported to SN's mother that the call to her on the night of June 7, 1999 was instigated by the nursing staff who felt that such a pretext was necessary in order to provide SN's mother with information as to the critical nature of his condition. In fact, SN's condition precluded him from taking such a step on his own. The nursing staff did not feel empowered by the NVMHI administration to contact the doctor directly, to call SN's mother directly or to call for an ambulance. The nursing staff was highly frustrated by their perceived inability to act on behalf of their patient.

One additional issue should be noted. Although not likely to have played a part in the death of SN, the diagnosis of neuro-malignant syndrome (NMS) made while SN was at Dejarnette, prior to 1990, was not properly carried forward in the medical records. It appears that the NVMHI treatment team was unaware that SN had a reported adverse reaction to haloperidol. As a result, this potential problem was not communicated to the Fairfax Hospital ER doctors who administered 2 mg IV haloperidol to calm SN in the early morning of June 8, 1999. While Dr. Leslie concludes that SN probably did not have NMS, the failure to carry this information in an appropriate manner is indicative of a "systems" problem which should be addressed.

Summary: Dr. Leslie summarized this case as follows:

> The patient had a severe mental illness characterized by altered thought processes, compulsive behaviors, oppositional behavior and, importantly, poor abstract reasoning (with documented limited learning and cognitive abilities). A patient being able to verbalize necessary dietary restrictions does not mean they have the impulse control and reasoning ability to carry out appropriate choices. At NVMHI, the patient's dangerous eating behaviors were not adequately monitored and certainly not consequenced. Rising cholesterols and triglycerides for months before his acute illness were not addressed. The

> significance of abnormal glucose was not recognized and the diagnosis of diabetes mellitus was missed. Increases in thirst and fluid intake were not correlated with lab evidence of elevated glucose. At the beginning of the acute illness, the patient was twice not seen in a timely fashion by the doctor on call, appropriate labs were not drawn, and there was poor communication between nursing and medical staff.

In addition to Dr. Leslie's finding, it appears that while his diet was controlled at WSH there were sufficient indicators that SN suffered from diabetes and a definitive diagnoses should have been conducted prior to his transfer to NVMHI. Had SN been diagnosed with diabetes while at WSH, he may not have been transferred. Even if SN was transferred, this vital diagnosis may well have altered the course of treatment SN received at NVMHI.

V. RECOMMENDATIONS

A. Litigation

The Department of Justice has entered into a Consent Decree with the Commonwealth of Virginia which requires a variety of remedial actions designed to provide patients with appropriate medical care at NVMHI. As a result of the death of SN and another NVMHI patient, the Justice Department reopened the case and amended the Consent Decree to require additional remediation. The estate of SN has retained private counsel and filed a notice of claim against the Commonwealth, and intends to pursue a wrongful death claim. As a result, there is no need for DRVD to implement separate litigation on behalf of SN. Further, there appears to be no basis for criminal charges against any of the persons involved in the care of SN.

B. Systemic Changes

The recommendations of Dr. Catherine Leslie appear to be appropriate and should be immediately implemented by DMHMRSAS (see attachment). In addition, there should be some protocol instituted to insure that when a patient is being transferred from one DMHMRSAS facility to another, the receiving institution is a full partner in the process. This would insure that the current institution fully understands the ability of the receiving institution to provide for the needs of the patient. It is not clear that the WSH discharge planning team fully comprehended the difficulties that NVMHI would have in providing for the needs of SN, although they clearly should appreciate the differences between a short-term and long-term care facility.

C. Monitoring

DRVD will monitor implementation of the settlement reached between NVMHI and the Department of Justice and the recommendations of Dr. Leslie regarding the provision of medical care to the patients at NVMHI. DRVD will work closely with the Department of Justice, the Inspector General for DMHMRSAS, the NVMHI administration, and the DMHMRSAS Office of Human Rights on medical care and human rights issues relating to residents of NVMHI and their families.